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How can a nurse intervention help people with newly diagnosed epilepsy? A qualitative study (of patients' views)

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The aim was to describe the patients' views of the challenges posed by a new diagnosis of epilepsy and their assessment of a nurse intervention. Neurologists in South-East England referred patients into the study. Following a trial of a nurse intervention a subgroup of patients were purposefully identified for in-depth interviews. Transcriptions of tape-recorded interviews were analysed using qualitative methodology. We found that younger people with epilepsy seemed to experience more trouble with driving, jobs and managing their lives in the context of new epilepsy, while older people saw epilepsy as just another illness to cope with. Patients reported difficulty in remembering what their doctors told them which they attributed partly to lack of time available in the consultation. They valued the time, and the technique of probing with explanations used by the nurse. The nurse intervention was seen as useful in making sense of symptoms, tests, risk management, and driving regulations and in helping manage their medicine taking. We conclude that people with newly diagnosed epilepsy face different challenges, some of which are related to their age at diagnosis. Patients reported help from the nurse with understanding the diagnosis, tests, risk management and taking their medication. Follow-up is necessary to measure behavioural effects on self-management in the long run.

Key words: epilepsy; nurse specialist; health education; qualitative methods.

INTRODUCTION

Epilepsy is as common as non-insulin dependent diabetes[1,2]. In both disorders patients need information and support to manage their condition. In the United Kingdom (UK) special nurses have increasingly provided information and support for patients with diabetes, and this development in teamwork has satisfied patients[1]. But evidence suggests that generally patients with epilepsy have not received advice and support through a structured teamwork approach[3,4].

We set up nurse-run epilepsy clinics in primary care, and evaluated the effect using quantitative and qualitative techniques[5–7]. Patient attendance was good (81%), and patients were satisfied, particularly with advice given on social issues. The initial diagnosis of epilepsy had occurred on average 28 years before, and at a time in the past this had required patients to adjust mentally and emotionally, and learn to cope with the condition. Patients reported they had been provided with too little information at the beginning. Lack of support and information in the context of a stigmatizing diagnosis was perceived in a particularly negative way. A man who had been told by his specialist that he had epilepsy, without any further information or support, said: 'It was as if someone had slapped me in the face'[7]. His family doctor had not given him information either, so he felt: 'I was left high and dry'[7]. Patients speculated that information and support would be most beneficial if it was begun

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when they had been first diagnosed. For example a woman said: 'Maybe if I had spoken to someone properly how I did with the nurse the other week, then maybe I might have come to terms with it sooner'[7].

We decided to test this patient-held belief by means of a randomized controlled trial. Between 1996 and 1998, seven neurologists prospectively recruited people over 16 years of age with epilepsy who had been newly diagnosed at five hospitals in South-East England. The criteria for recruitment were:- patients with epilepsy involving two or more attacks and the initiation of antiepileptic drugs. The results in terms of four quantitative outcomes have been reported separately[8]. In the UK, all patients are seen by their family doctor who initiates specialist referral. So all patients in the trial had seen their general practitioner and neurologist usually on two or more occasions. When the neurologist was able to confirm a new diagnosis of epilepsy, the patient was invited into the trial. Those who agreed (102/108,80%) to participate were randomized to a nurse intervention plus usual care, or usual medical care.

The nurse intervention has been described in detail[9]. It included advice on driving, self-help groups, epilepsy types and causes, side effects and interactions of antiepilepsy drugs, and risk avoidance. In addition, patients in this trial were responding to the bad news of a new diagnosis. The nurses therefore tailored information and advice provided according to patients' expressed needs, and according to their individual need for advice on diverse topics such as driving, contraception and pregnancy. When it seemed appropriate nurses provided topic-related leaflets, and lent books or videotape recordings. Nurse appointments were offered at the local hospital where the patient was usually seen by their neurologist. The first appointment usually lasted 45–50 minutes; three months later a second appointment was offered of 15–20 minutes. Of 54 patients offered a nurse intervention, 44 (81%) attended.

The aim of this paper is to describe and assess the nurse intervention from the patients' point of view. This was addressed using qualitative methods which allow issues of importance for patients to be identified and examined in depth[10].

METHODS

As part of the quantitative wing of the trial, 90 patients with newly diagnosed epilepsy returned questionnaires at baseline and six months later. Their mean age was 40 years (range 17–83), and 51% were men. In order not to bias responses to questionnaires, patients were interviewed after they had returned the second (outcome) questionnaire. Initially pilot interviews were undertaken and recorded by a research nurse (RS). These were focussed interviews about the impact of the diagnosis and patients' coping strategies. Transcriptions of these recordings were used by LR and MM to draw up a list of themes, which were used subsequently, and incorporated into semi-structured interviews. A subgroup of 31 patients was purposefully identified for interview. Criteria for selection were that the group would be representative in terms of age and sex of the larger group of 90, but that two thirds would have been randomized to the nurse intervention arm of the trial. The interviewer (RS) offered to visit the patients' home. Interviews were tape-recorded, transcribed and analysed with the aid of Ethnograph vs. 5.0 software. Two co-raters (LR and IK) identified coding categories and three raters (LR, MM, IK) checked the consistency of coding. We obtained multicentre research ethics approval for this.

RESULTS

Of the patients approached, 24/31 (77%) agreed to be interviewed. Five patients refused to be interviewed. Two were not contactable. Two interview tapes were discarded due to poor sound quality. A total of 22 transcripts were analysed (seven control and 15 intervention). Fifteen patients had seen the nurse and this analysis is based on their transcripts. Four themes were identified, three of which related specifically to the nurse intervention: the challenges that epilepsy created for patients; what they learned, valued or remembered from seeing a nurse; the influence of time on their consultations with the doctor or nurse; and some reasons for not feeling helped by the nurse intervention.

1. Challenges for patients

Over half the patients described difficulties in learning about their condition and self-management and identified factors that had helped or hindered this process. Some patients specifically reported, 'poor memory'. One said,

> my mind isn't as clear as it ought to be
> (M, age 73).

When patients commented about consultations with their doctor, they reported that they had often forgotten to ask important questions, particularly when time was short. Or, patients reported that doctors gave them information when they had not asked questions. In contrast to this, patients stated that the nurse probed with questions on many issues, and this process

reminded them, or focussed them on the questions that had occurred to them before. This technique of enquiry, which was linked to explaining in response to the patients' own questions, meant that they were more likely to remember the explanations. A patient said about his doctor,

> I was told the answers before I knew the questions, and that is not really the way to learn, is it?

In contrast he said,

> the nurse, well, reinforced the questions (M, age 32).

Cognitive and affective aspects of learning and adjustment to a new diagnosis of epilepsy appeared to present different challenges at different stages of life. Younger and middle aged people generally reported more difficulty in coping with the diagnosis. They described how they were adjusting to the effects of the diagnosis on themselves and others. Many had difficulty coming to terms with not driving, and managing their relationships with the Driving Vehicle Licensing Authority and insurers. One patient commenting on her doctor said,

> He didn't even tell me that I shouldn't drive or anything like that, so I just carried on (driving) (F, age 22).

A middle-aged man reported on the difficulty that he had in coming to terms with sitting as a passenger when his wife was driving their sports car. He said that he valued the nurse seeing him and helping him discuss these feelings with his wife, which made him feel a little 'easier'. Now he felt his wife was,

> a little bit more on my side (M, age 51).

Elderly patients frequently had other medical problems, and in this context a new diagnosis of epilepsy seemed to disturb them less. For example a 64 year old woman commented:

> I think because all these years I have had to cope with a cardiac problem, it's just something more that I have taken on board, you know.

The challenge for these older people was to learn about their new condition, in addition to managing their current ones, which included the possible complications of adding new drugs to their previous drug regime.

2. What specifically patients learned or valued from the nurse input

Patients were able to identify specific information, aids to remembering, and support which they found useful. Many were still coming to terms with the diagnosis. Some commented that they had been able to accept it more when they learned from the nurse how common it was. Some had found a positive diagnosis of epilepsy in the context of normal test results, puzzling. The nurse had explained to them how this was possible, and that a normal test result did not necessarily undermine their clinical diagnosis. One patient accepted that she had epilepsy but had not realised, until she saw the nurse, that the funny tastes and smells she had experienced might also be part of her epilepsy. She described relief at learning that these phenomena were consistent with a type of epilepsy, and that

> I am not going daft! (F, age 40).

Several patients described the nurse providing advice on reducing the risks associated with bathing, showering and swimming, which all but one said they had implemented. A few patients described being given a card by the nurse, which they carried to help with diagnosis and management in case they had an attack in a public place. Over half the patients reported that having identified a particular problem or area in which they needed more information, the nurse had provided a leaflet or some written information, which had helped them to understand or learn to cope with the problem more efficiently.

Over a third of patients identified specific difficulties in remembering to take their pills in a way that had been prescribed. Sometimes this was attributed to problems with memory, which they associated with epilepsy. Some of them had bought pill packs from the nurse, which helped to remind them what they should take on each day of the week. Other aspects of pill taking which patients described having learned were: what to do when they had forgotten to take tablets; what the side effects of tablets were; and their drug's interaction with other tablets, such as contraceptives, and about the availability of drugs free on prescription. One said

> She sent me a form through, as my doctor didn't tell me that I didn't have to pay for them (medication) (F, age 49).

Deciding how to manage their activities and role obligations was exceedingly difficult for many people, and the nurse intervention appeared to provide a package of time, plus information and support whilst they reconfigured their lives. In our previous study a patient with chronic epilepsy recounted that after the diagnosis of epilepsy, he had been left 'high and dry'. In this study a man with new epilepsy who was randomized to see the nurse stated,

> I found out more from the specialist nurse than I did from anyone else. . . I didn't feel I was left high and dry, which is a good thing to my mind. (M, age 37).

3. The effect of time

Despite recounting long delays, with uncertainty over diagnosis and management going on often for a year or more, patients did not blame their doctors. More than half of the patients interpreted the main problem as being how many people UK doctors have to deal with, and the consequent lack of time to manage each one of them. One described interaction with his family doctor as follows:

> When you go back to see the doctor, it's all very short lived, and you either don't remember to ask the question, or you don't remember all the questions you'd like to have asked. If I have five or ten minutes, I'll remember it, but if it's two or three minutes and the interview is brought to a conclusion by the doctor. . .

He went on to describe a typical consultation:

> 'Is everything OK?' and I say 'Yeah, everything is OK'. And there is something at the back of my mind and I can't remember what it is. And they go 'Right, you can ask me anytime. So you're alright then now. OK, Goodbye. You've got your medication?' And it's over with. (M, age 37).

Another, commenting on his neurologist said:

> A specialists time is valuable, they are all overworked. (M, age 76).

A few patients were more critical, for example, one said:

> He was always, you know like, sort of pushing you out of the door. (F, age 17).

Doctors were perceived as not having enough time, whilst the nurse was perceived as having much more time available. In this context patients reported they had been enabled to identify the questions which concerned them and find the answers.

4. Why some were not helped

A minority of patients expressed a view that seeing the nurse did not help them. They too had explanations for this. One patient expressed anger that she was misdiagnosed at the beginning. She was experiencing difficulties with getting to work which was 25 miles away from her home, without a car. She described a denying coping style as follows:

> If I don't want something to happen then I forget about it, don't think about it and it will go away. If I've got a decision to make and I don't want to make a decision, I sort of sweep it under the carpet sort of thing. I'm that sort of a person. (F, age 50).

This patient described perceiving a window of opportunity earlier on, during which she felt the diagnosis had been delayed and that she had been let down.

Another patient identified a short period during which he might have found the nurse input helpful:

> In those first two weeks if she'd been there, that's exactly what I wanted really. I must say a lot of my worries had gone because this is three months later. (M, age 29)

Each patient had received the offer of two appointments, one commented that:

> It was nice to see her again, but I don't think I learned a lot more (F, age 68).

However, another acknowledged the usefulness of a second visit saying:

> I think she explained everything better, especially last time. I mean you do forget. (F, age 40).

DISCUSSION AND CONCLUSIONS

So far as we know this is the first qualitative study of the effects of a nurse intervention for patients with newly diagnosed epilepsy. We found that for young and middle-aged people, new onset epilepsy represented a biographical disruption[11], in which issues of driving, work, and self-image were important. For older people epilepsy seemed to be just another illness with complex issues for self-management. These age linked differences have also been described in adjustment to stroke[12].

Some patients with epilepsy reported difficulty in remembering their questions, and in remembering information about self-management. This phenomenon may be organic; some were older and had previously suffered a stroke. Using electroencephalography Binnie *et al.* have found that subclinical

epileptic discharges in people with epilepsy may be associated with loss of ability to take in information[13]. This functional receptive difficulty may be more likely to occur when patients have been newly diagnosed, and have not yet achieved full epilepsy control.

Many patients expressed concern about the duration of time between their first epilepsy attack, achieving a diagnosis, and effective control of symptoms, which was frequently a year or more. Patients did not generally blame doctors for the lack of access or time provided to see them. They did report that learning about epilepsy was easier in the context that more time was provided by the epilepsy nurse. Specific help was acknowledged in understanding the diagnosis, tests, risk management, and taking their medication.

Patients reported gains at a cognitive and affective level from the nurse intervention. They linked learning to the nurse's approach of enquiring about different areas, and providing information responsively. Tuckett *et al*. have suggested that doctors find it difficult to adopt this educational style[14]. Dilorio and Manteuffel suggest that nurses receive more training to undertake this health education role[15].

The challenges of coming to terms with the diagnosis and self-management were different for patients of different ages. In this context the nurse provided time, and a probing with questions approach, which enabled patients to remember their own questions, and to remember the specific information they required. Our study supports the hypothesis that nurse intervention is valued by most patients when they are first diagnosed with epilepsy. More research will be necessary to describe whether this leads to gains in knowledge and self-management for people with epilepsy in the long run.

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REFERENCES

1. Murphy, E., Kinmonth, A. L. and Marteau, T. General practice based diabetes surveillance: the views of patients. *British Journal of General Practice* 1992; **2**: 279–283.
2. Ridsdale, L., Robins, D., Fitzgerald, A., Jeffery, S., McGee, L. and the Epilepsy Care Evaluation Group. Epilepsy monitoring and advice: general practitioners' views, current practice and patients' preferences. *British Journal of General Practice* 1996; **46**: 11–14.
3. Scambler, G. *Epilepsy*. London, Routledge, 1989.
4. Jacoby, A., Graham-Jones, S., Baker, G., Ratoff, L., Heyes, J., Dewey, M. and Chadwick, D. A general practice records audit of the process of care for people with epilepsy. *British Journal of General Practice* 1996; **46**: 595–599.
5. Scambler, A., Scamber, G., Ridsdale, L. and Robins, D. Towards an evaluation of an epilepsy nurse specialist in primary care. *Seizure* 1996; **5**: 225–258.
6. Ridsdale, L., Robins, D., Cryer, C., Williams, H. and the Epilepsy Care Evaluation Group. Feasibility and effect of nurse-run clinics in general practice: a randomized controlled trial. *BMJ* 1997; **314**: 20–22.
7. Risdale, L., Morgan, M. and O'Connor, C. Promoting self-care in epilepsy: the views of patients on the advice they had received from specialists, family doctors and an epilepsy nurse. *Patient Education Counsel* 1999; **37**: 43–47.
8. Ridsdale, L., Kwan, I., Cryer, D. and the Epilepsy Care Evaluation Group. Newly diagnosed epilepsy: can nurse specialists help? A randomized controlled trial. *Epilepsia* 2000; **41**: 1014–1019.
9. Kwan, I., Ridsdale, L. and Robins, D. An epilepsy care package: a nurse specialist's role. *Journal of Neuroscience Nursing* 2000; **32**: 142–152.
10. Morgan, M. and Ridsdale, L. An approach to evidence from qualitiative research. In: *Evidence-based Practice in Primary Care* (Ed. L. Ridsdale). Edinburgh, Churchill Livingstone, 1998: pp. 31–43.
11. Bury, M. Chronic Illness as biographical disruption. *Sociol Health Illn* 1982; **4**: 167–182.
12. Pound, P., Gompertz, P. and Ebrahim, S. Illness in the context of older age: the case of stroke. *Sociol Health Illn* 1998; **20**: 489–506.
13. Binnie, C. D. Cognitive impairment—is it inevitable? *Seizure* 1994; **3** (Suppl. A): 17–21: discussion 21–22.
14. Tuckett, D. A., Boulton, M., Olson, C. and Williams, A. *Meetings Between Experts: An Approach to Sharing Ideas in Medical Consultations*. London, Tavistock Publications, 1985.
15. Dilorio, C. and Manteuffel, B. Preferences concerning epilepsy education: opinions of nurses, physicians, and persons with epilepsy. *Journal of Neuroscience Nursing* 1995; **27**: 29–34.